8-6-2011

Misinformation in Healthcare Social Networks: Contributing Factors

Victoria Kisekka
State University of New York, vkisekka@buffalo.edu

Raj Sharman
State University of New York at Buffalo, rsharman@buffalo.edu

Ranjit Singh
State University of New York, rs10@buffalo.edu

Gurdev Singh
State University of New York, gsingh4@buffalo.edu

Misinformation in Healthcare Social Networks: Contributing Factors

Victoria Kisekka
School of Management
State University of New York, Buffalo
vkisekka@buffalo.edu

Raj Sharman
School of Management
State University of New York, Buffalo
rsharman@buffalo.edu

Ranjit Singh
Family Medicine Research Institute
State University of New York at Buffalo
rs10@buffalo.edu

Gurdev Singh
Family Medicine Research Institute
State University of New York at Buffalo
gsingh4@buffalo.edu

ABSTRACT

There has been a steady increase in the amount of information published on the internet in the past ten years. In the healthcare domain, patients are increasingly exchanging medical information on online social networks and engaging in self care as a result. This trend has concerned many researchers who have studied and confirmed the existence of misinformation on the internet. This research is a work in progress investigating how online social networks affect patient safety**.** The research question is: What are the factors contributing to the amount of misinformation in healthcare social networks? In particular, this research explores the critical factors that influence the extent of misinformation about diabetes on a diabetes social network. A total of 100 discussion threads will be collected and regression techniques will be used to analyze the data.

Keywords

Online healthcare social networks, misinformation about diabetes, factors contributing to misinformation, factors affecting patient safety.

INTRODUCTION

The rising popularity of online social networks has led to an increase in the number of web applications and the amount of information published on the internet. It has also become relatively easy for end-users to create web pages and share information with other internet users. In the healthcare domain, patients regularly search for health information on the internet. The 2002 *Pew Internet & American Life Project* estimated that "80% of adult internet users, or about 93 million Americans, have searched for at least one of 16 major health topics online" (Fox and Fallows, 2003). The report concluded that "this makes the act of looking for health or medical information one of the most popular activities online" (Fox and Fallows, 2003) .

Despite the growing number of people accessing health information on online social networks[1], however, the quality of this information is questionable. Several studies have indicated that medical information on the internet is sometimes ambiguous, incomplete, or inaccurate (Davison, 1997; Eysenbach, Powell, Kuss, and Sa, 2002; Huberman, Romero, and Wu,

[1] The words online social network and online communities are used interchangeably. Online communities are, in essence, a form of social networks with some specific characteristics such as commonality of interests among participants. However, please note that this paper does not make use of social network analysis tools in the traditional sense.

2009; Murray, Lo, Pollack, Donelan, Catania, Lee, Zapert, and Turner,, 2003; Scanfeld, Scanfeld, and Larson, 2010). These studies confirmed the presence of misinformation on online social networks. For example, a pilot study of three consumer health social networking websites concluded that only 48% of the postings contained medical content and 54% of those were either incomplete or contained errors (Tsai, Tsai, Zeng-Treitler, and Liang, 2007). Another study found that out of 167 dietary recommendations, "the total number of web sites that provided information that was inconsistent with Canadian guidelines per each keyword search was 25 (29.8%) for "diet," 11 (13.1%) for "food," and 48 (57.1%) for "nutrition"(Davison, 1997). These findings reinforce the need to understand online healthcare information exchange and how the information exchanged affects patient safety.

In spite of all these studies, existing literature has been weak in identifying the significant factors responsible for misinformation in online healthcare social networks. Gunther Eysenbach wrote an article that contains a comprehensive review of several studies of how cancer patients use the internet and possible effects of internet use on cancer outcomes (Eysenbach, et al., 2002). In this article, Eysenbach compares the proportion of inaccurate health information on the internet across different medical conditions. His findings conclude that topics on certain diseases contain more misinformation than others. For instance, the percentage of inaccurate information found on prostate cancer and breast cancer websites was 4% and 5.1% respectively. On the other hand had 88.9% of information about nutrition was inaccurate (Eysenbach, et al., 2002).

The motivation for this research is the amount and the differing percentages of inaccurate information across the different healthcare topics. Researchers exploring the inaccuracies of healthcare information on social networks have done a tremendous job in developing empirical studies that measure and confirm the existence of misinformation on social networks (Davison, 1997; Scanfeld, et al., 2010; Tsai, et al., 2007). Other literature in this area has been focused on tools for assessing and measuring the quality of health information published on the internet (Hargrave, Hargrave, and Bouffet, 2006; Meric et al., 2002; Purcell, Wilson, and Delamothe, 2002). As stated earlier, literature has been weak in making the linkage between the prevalence of health misinformation on online social networks and the factors contributing to misinformation. Eysenbach acknowledges this need by stating that "rather than getting bogged down by the question of how much information is inaccurate, one could analyze where and why gaps exist between evidence based medicine and health information on the Internet" (Eysenbach, 2003). This study seeks to reduce this gap by answering the following question: What are the critical factors that influence the extent of misinformation about Diabetes on online social networks?

We are studying online social communities because they connect patients and facilitate the exchange of healthcare information and advice amongst patients. This study focuses on one specific disease and healthcare social network; diabetes

and TuDiabetes respectively. TuDiabetes is an online social network devoted to helping people who are suffering from all types of diabetes by educating them through discussions and sharing information about how to live with the disease. We chose to use TuDiabetes because it is currently the most widely used online social network by diabetes patients. More detailed information regarding our choice of online social network is provided in the *Method* section. We chose diabetes because the number of US adults treated for diabetes has doubled between 1996 and 2007. In this period the number of people aged 65 and older treated for diabetes increased from 4.3 million to 8 million, outpatient treatment costs for diabetes doubled from about $5 billion to $10 billion, and total prescription drug costs increased fourfold from $4 billion to $19 billion.

By engaging in this research, we hope to improve patient safety which is often affected by erroneous and/or misleading medical information exchanged on social networks. The critical factors identified in this research will have significant implications to healthcare policies and will provide the necessary information that will prioritize research geared towards improving patient safety at individual and population levels. For example, the critical factors identified could be used by healthcare social networks as the basis for improving the quality of information exchanged among users. Furthermore, results from this study will act as an impetus to the establishment of healthcare policies that would ensure that factors contributing to healthcare misinformation on online social networks are reduced.

RESEARCH MODEL AND HYPOTHESES

Figure 1 presents the research constructs and model proposed in this research-in-progress.

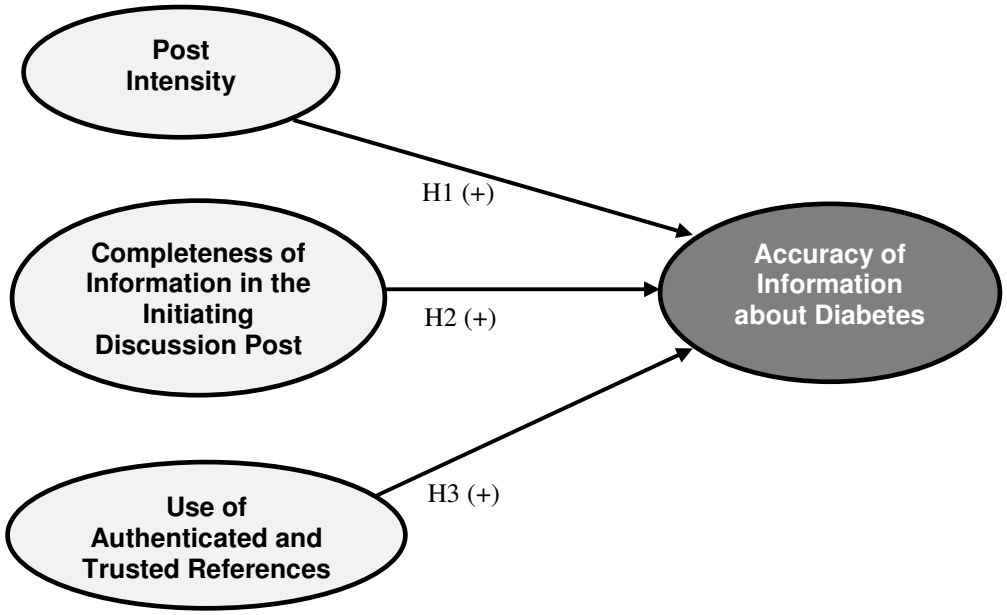

Figure 1. Critical factors affecting information accuracy about Diabetes

The key research construct in this study is the extent of the accuracy of information about diabetes on online social networks. The research seeks to investigate critical factors that affect the accuracy of information about diabetes in online communities. The unit of analysis is a discussion thread. The accuracy of information will be obtained by administering a large sample of threads to a group of physicians specializing in the diagnosis and treatment of diabetes. The independent variables are post intensity, completeness of information in the initiating discussion post, and use of authenticated and trusted references.

Post intensity: In this research, post intensity is defined as the number of posts per user in a thread. Post intensity will be determined by the extent of user participation and the number of discussion posts.

Extent of user participation: User participation is the pith of social networks which use the Web 2.0 framework. Web 2.0 is a term used to refer to user centric technologies where users actively contribute to the creation and editing of content through collaboration. Web 2.0 based applications are dynamic in nature; a published entry may be extended, corrected, or reworked within a short period of time. There have been influential studies suggesting that the quality of user-driven content improves as the number of users contributing increases (Magnus, 2008). It is also generally argued (*particularly in the crowd sourcing*

literature), that large groups of people have more collective intelligence than small groups (Surowiecki and Silverman, 2007). Therefore, as an increased number of users pool their knowledge, the resulting answers get better than those gathered separately from a small number of individuals. Another study assessed the frequency of error correction on *Wikipedia*, a popular Web 2.0 web site, and found that inaccurate entries were corrected fairly quickly (Magnus, 2008). The *Wikipedia* theory is relevant but does not account for social networks where a discussion post cannot be modified by anyone other than the author. The number of users is important in our study because of the theory of apomediation. According to this theory, apomediaries such as web 2.0 applications, will direct users to relevant accurate information in the absence of intermediaries such as health professionals, researchers, etc (Eysenbach, 2008). Under this theory, users rely less on experts and more on guidance from other users. In other words, people share information regarding their experiences with certain diseases, treatments, symptoms, etc. to provide collective wisdom that patients experiencing the same conditions can use to make decisions. *TuDiabetes* meets the definition of an apomediation environment as described in (Eysenbach, 2008). Based on the supporting literature our expectation is that the extent of user participation should positively impact the accuracy of Diabetes information on an online social network. In this research, we define a discussion post as a reply or comment to the question that initiated the discussion thread. A discussion thread is a grouping of discussions, responses or comments about a specific topic. A high number of discussion posts may be attributed to a high number of users participating or the frequency with which users are participating.

Number of discussion posts: To a certain degree, the number of users participating in a thread informs on the interest in the topic and the number of posts informs on the intensity of interest. An increased number of discussion posts due to user participation indicate that the number of ideas or information exchanged is high. This assumption is based on several studies in system design which found a positive association between user participation and knowledge sharing (Fischer and Ostwald, 2002). Therefore, active users may explore complex diabetes-related health topics through questions thereby eliciting participation and in the process, helpful medical information may ensue. This leads to the following hypothesis:

Hypothesis 1: Post intensity participating positively impacts the accuracy information in the thread relating to diabetes

Completeness of information in the initiating discussion post: Completeness of information is a dimension of information quality. Other dimensions/elements of information quality defined in existing literature include: accuracy, believability, reputation, objectivity (Wang and Strong, 1996), correctness, unambiguous, and meaningfulness (Wand and Wang, 1996). Incomplete question(s) in the post initiating the discussion may induce responses that could be classified as erroneous depending on one's understanding of the question. Often posters seeking advice regardless of whether it is for the purposes of diagnosis, medication, or advice are not aware of what constitutes relevant and appropriate information that one needs to

convey in order to receive appropriate responses. Often the context is intentionally or unintentionally not conveyed. The lack of appropriate information portrayed in a proper context is not part of the initial question. In the event that the information provided is insufficient, there are two possible approaches that other members participating in the thread could take: (a) seek clarification and/or (b) make suitable assumptions and answer the post. Unlike other services that one may purchase where the buyer is more able to express his requirements and evaluate the quality of service, it is extremely difficult to provide information with complete clarity for diagnosis or treatment because the person posting the question or initiating the thread may not be completely aware of what information is needed to provide a useful answer. This leads to the following hypothesis:

Hypothesis 2: Completeness of Information in the initiating discussion thread positively impacts the accuracy information in the thread relating to diabetes.

Authenticated and trusted references: Discussion posts containing or referencing legitimate sources of information about Diabetes may contain fewer errors compared to threads and posts which do not contain legitimate references. Use of authentic sources such as the American Diabetes Association will direct users to trusted sources of information where they can find correct answers to their questions. We define an authenticated and trusted reference as a repository of data or information that is considered to be credible and reliable based on the author and/or publisher. Literature in the e-commerce area informs us that trust is important for e-commerce. Trust is defined as "the subjective assessment of one party that another party will perform a particular transaction according to his or her confident expectations, in an environment characterized by uncertainty" (Ba and Pavlou, 2002). Research shows that trust plays a critical role in promoting information and knowledge sharing among the community members (Chiu, Hsu, and Wang, 2006; Hsu, Ju, Yen, and Chang, 2007; Ridings, Gefen, and Arinze, 2002). This leads to the last hypothesis:

Hypothesis 3: *Threads containing posts with authenticated and trusted sources positively impact the accuracy of information in the thread relating to diabetes.*

There are other variables that may affect the measurements of the proposed variables. The known confounding variables in this study are: the education background of the users exchanging information on TuDiabetes and spam posts where users promoting medical products provide biased responses.

METHOD

As mentioned in the abstract, this research is still in progress. A total of 100 discussion threads are being analyzed. The first criterion for selecting the threads was clarity of the thread question. For example, a question with several different

interpretations will induce responses that could be classified as erroneous depending on one's understanding of the question. The second criterion is type of content in the thread topic. The threads included in the study contain discussions about treatments, symptoms, care, diagnosis and other information specific to diabetes.

The choice of using TuDiabetes social network in this research was based on the popularity of the website and availability of a forum to facilitate exchange of information about diabetes. A web tool called *popuri.us* was used. *Popuri.us* shows the popularity of any website based on different ranks. Other social networks considered for this study include *Juvenation, My Diabetes Socialnetwork,* and *Diabetic Rockstar.* The relevant ranks considered for the diabetes social networks are *Alexa*, *Compete*, and *Yahoo BackLinks* which all rank a specific website based on the amount of traffic the website receives and the number of other websites linking to the website in question. The TuDiabetes social network had a high popularity ranking from all three ranks so it contained sufficient data for our research problem.

RESEARCH PLAN AND METHODOLOGY

Data Collection

Table 1 is a summary showing each hypothesis and the associated measure.

Hypothesis	Measure
Post intensity positively impacts the accuracy of information in the thread relating to diabetes	Count of unique user names within a discussion thread, Count of discussion posts within a discussion thread
Completeness of information in the initiating discussion thread positively impacts accuracy of information in the thread relating to diabetes	A rating on a five-point numeric scale
Threads containing posts with authenticated and trusted sources positively impact the accuracy information in the thread relating to diabetes	Count of the number of legitimate sources of diabetes information referenced in the discussion thread

Table 1. Hypotheses and Measures

The following paragraphs discuss the data collection and analysis process summarized in Table 1.

Post Intensity: Post intensity will be determined by:

a) The number of users participating: The number of users participating in a single discussion thread will be obtained by counting the total number of unique user names within a thread. Each user in the TuDiabetes user community has a unique user name associated with his/her account. By counting the unique user names, we will have the total number of users participating in a single thread. This information is publicly available on the TuDiabetes website.

b) Number of Discussion Posts: The number of discussion posts in a thread publicly available on TuDiabetes.

Completeness of information in the initiating discussion post: A five-point numerical scale will be used by the physicians to rate the completeness of information in the initiating discussion post. A rating of 1 will be assigned if the post

initiating the discussion contains incomplete and ambiguous information that cannot be used to provide a useful answer. A rating of 5 will be assigned to a post containing unambiguous questions and the relevant information necessary to provide a useful answer.

Use of authenticated and trusted references: Each discussion post will be analyzed to identify authenticated and trusted references. Each reference will be carefully verified and validated to ensure authenticity. The total number of posts which contain validated sources of diabetes treatment, care, diagnosis, and other related information will be counted.

Accuracy of Information about Diabetes: Data for the dependent variable will be obtained with the help of two physicians. Each physician will read through the posts that initiated the discussions and provide correct answers to the questions asked. Because some of the questions may require subjective answers, the answers to such questions as provided by the physicians may be different. This problem will be solved by having both physicians analyze such questions and provide a unanimous answer. The answer key from the physicians will then be used to rate each discussion post using a five-point numerical scale. Each post will be rated based on the correctness of the information provided. The average accuracy rating will then be calculated to determine the accuracy of the thread. For example, a rating of 1 will be assigned to a post containing incomplete, incorrect, and ambiguous answers while a rating of 5 will be assigned to a post containing complete, accurate, and clear answers to the questions asked. Two raters will independently assign a rating to each post and inter-rater reliability will be measured. More about inter-rate reliability is covered later on in this paper.

Regression Model

The data will be analyzed using regression techniques after testing for the standard assumptions for regression.

Reliability

The five-point numerical scale that will be used to measure the accuracy of information about diabetes has never been used in prior studies. In order to establish reliability of the rating model, inter-rater reliability will be measured. Inter-rater reliability is a measure of the degree of agreement between different raters who each rate a sample of subjects on a nominal scale. Fleiss' Kappa, a common statistical measure for inter-rater reliability, will be used to assess the reliability of the ratings assigned. For more information about Fleiss' Kappa, refer to (Fleiss, 1971; Landis and Koch, 1977; Sim and Wright, 2005).

CONCLUSION

This research-in-progress attempts to contribute to our understanding the factors that affect online communities. The study specifically examines the extent of participation, the completeness of the information and use of trusted sources in online communities that deal with diabetes. To our knowledge, there is no study developing a theoretical model to explain the

extent of misinformation and the critical factors contributing to misinformation in the threads on TuDiabetes. When performing the data analysis, we rate the initiating post for completeness but this rating does not take into account later posts that may contain additional information and/or clarifications from the thread author. This limitation will be addressed in future work. Another limitation is that we do not take into consideration the possibility of some posts being highly informative compared to other posts in the thread. We will address this limitation in future work by identifying how informative each post is and how highly informative posts affect the overall accuracy of information in the thread. We would like to thank the reviews for their comments and suggestions for improving this research. Our future work will include factors specific to diabetes in the model.

REFERENCES

1. Ba, S., and Pavlou, P. A. (2002). Evidence of the effect of trust building technology in electronic markets: Price premiums and buyer behavior. *MIS quarterly, 26*(3), 243-268.
2. Chiu, C. M., Hsu, M. H., and Wang, E. T. G. (2006). Understanding knowledge sharing in virtual communities: An integration of social capital and social cognitive theories. *Decision Support Systems, 42*(3), 1872-1888.
3. Davison, K. The quality of dietary information on the World Wide Web. *Clinical performance and quality health care, 5*(2), 64.
4. Davison, K. (1997). The quality of dietary information on the World Wide Web. *Clinical performance and quality health care, 5*(2), 64.
5. Eysenbach, G. (2003). The impact of the Internet on cancer outcomes. *CA: A Cancer Journal for Clinicians, 53*(6), 356-371.
6. Eysenbach, G., Powell, J., Kuss, O., and Sa, E. (2002). Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. *JAMA, 287*(20), 2691.
7. Fischer, G., and Ostwald, J. (2002). Seeding, evolutionary growth, and reseeding: Enriching participatory design with informed participation.
8. Fleiss, J. (1971). Measuring nominal scale agreement among many raters. *Psychological Bulletin, 76*(5), 378-382.
9. Fox, S., and Fallows, D. (2003). Internet health resources: health searches and email have become more commonplace, but there is room for improvement in searches and overall Internet access: Pew Internet and American Life Project Washington DC.
10. Hargrave, D. R., Hargrave, U. A., and Bouffet, E. (2006). Quality of health information on the Internet in pediatric neuro-oncology. *Neuro-Oncology, 8*(2), 175-182. doi: 10.1215/15228517-2005-008.

11. Hsu, M. H., Ju, T. L., Yen, C. H., and Chang, C. M. (2007). Knowledge sharing behavior in virtual communities: The relationship between trust, self-efficacy, and outcome expectations. *International Journal of Human-Computer Studies, 65*(2), 153-169.
12. Huberman, B., Romero, D., and Wu, F. (2009). Social networks that matter: Twitter under the microscope. *First Monday, 14*(1), 8.
13. Landis, J., and Koch, G. (1977). The measurement of observer agreement for categorical data. *Biometrics, 33*(1), 159.
14. Magnus, P. (2008). Early response to false claims in Wikipedia. *First Monday, 13*(9).
15. Meric, F., Bernstam, E. V., Mirza, N. Q., Hunt, K. K., Ames, F. C., Ross, M. I., . . . Singletary, S. E. (2002). Breast cancer on the world wide web: cross sectional survey of quality of information and popularity of websites. *BMJ, 324*(7337), 577-581. doi: 10.1136/bmj.324.7337.577.
16. Murray, E., Lo, B., Pollack, L., Donelan, K., Catania, J., Lee, K., . . . Turner, R. (2003). The impact of health information on the Internet on health care and the physician-patient relationship: national US survey among 1.050 US physicians. *Journal Of Medical Internet Research, 5*(3).
17. Purcell, G. P., Wilson, P., and Delamothe, T. (2002). The Quality Of Health Information On The Internet: As For Any Other Medium It Varies Widely; Regulation Is Not The Answer. *BMJ: British Medical Journal, 324*(7337), 557-558.
18. Ridings, C. M., Gefen, D., and Arinze, B. (2002). Some antecedents and effects of trust in virtual communities. *The Journal of Strategic Information Systems, 11*(3-4), 271-295.
19. Scanfeld, D., Scanfeld, V., and Larson, E. (2010). Dissemination of health information through social networks: Twitter and antibiotics. *American journal of infection control, 38*(3), 182-188.
20. Sim, J., and Wright, C. C. (2005). The Kappa Statistic in Reliability Studies: Use, Interpretation, and Sample Size Requirements. *Physical Therapy, 85*(3), 257-268.
21. Surowiecki, J., and Silverman, M. (2007). The wisdom of crowds. *American Journal of Physics, 75*, 190.
22. Tsai, C., Tsai, S., Zeng-Treitler, Q., and Liang, B. (2007). Patient-centered consumer health social network websites: a pilot study of quality of user-generated health information.
23. Wand, Y., and Wang, R. Y. (1996). Anchoring data quality dimensions in ontological foundations. *Commun. ACM, 39*(11), 86-95. doi: 10.1145/240455.240479.

Wang, R. Y., and Strong, D. M. (1996). Beyond accuracy: What data quality means to data consumers. *Journal of management information systems, 12*(4), 5-33.